



The Honorable Cathy McMorris Rodgers  
Republican Leader  
Energy and Commerce Committee  
U.S. House of Representatives  
2322 Rayburn House Office Building  
Washington, D.C. 20515

Dear Republican Leader McMorris Rodgers:

The undersigned members of the Consortium for Constituents with Disabilities (CCD) write in response to your request for information on Disability Policies in the 21<sup>st</sup> Century: Building Opportunities for Work and Inclusion. CCD is the largest coalition of national organizations working together to advocate for Federal public policy that ensures the self-determination, independence, empowerment, integration and inclusion of children and adults with disabilities in all aspects of society free from racism, ableism, sexism, and xenophobia, as well as LGBTQ+ based discrimination and religious intolerance.

We thank you for this comprehensive and thoughtful examination of many of the challenges facing people with disabilities who rely on Medicaid to live and work in their communities. We hope that our comments, developed by many of our different task forces, will be helpful and we look forward to working with you to move these policy solutions forward. We will address each of your questions in turn.

#### **1.1 Regarding Medicaid's institutional bias:**

##### ***A. How can Congress reduce or eliminate the institutional bias in Medicaid?***

CCD appreciates the Committee's interest in rectifying Medicaid's institutional bias, which can result in people with disabilities receiving services in less integrated settings than is appropriate to their needs. As Congress recognized when passing the Americans with Disabilities Act (the "ADA"), full integration of people with disabilities promotes their ability to thrive in and contribute to their communities.<sup>1</sup> Because of the often devastating personal and economic consequences of unnecessary institutionalization, CCD reiterates its strong support for reducing, and ultimately eliminating, Medicaid's institutional bias.

There are a number of steps that Congress could take to reduce the institutional bias. Incremental measures that would begin to shift Medicaid's bias toward integrated settings include, but are not limited to, the following: addressing critical workforce shortages among workers that provide home and community-based services (HCBS); making Money Follows the Person and Spousal Impoverishment protections permanent; and making certain HCBS optional

Medicaid services mandatory, and thus available to a larger group of enrollees. In the long-term, we believe that more fundamental structural changes to Medicaid will need to be enacted to eliminate the institutional bias.

The first issue we must address is the workforce crisis. According to the most recent Staff Stability Survey conducted by National Core Indicators® Intellectual and Developmental Disabilities (NCI), the national turnover rate among Direct Support Professionals (DSPs) is approximately 44%, but ranges as high as 79.5% in some states.<sup>2</sup> In addition, vacancy rates for DSPs have increased from 8.5% in 2019 to 12.3% in 2020—a roughly 45% increase. The loss of DSPs across the field has left many individuals without stable access to HCBS. In fact, a 2021 survey of community providers across the country indicated that the devastating impacts of the COVID-19 pandemic and continued exodus of DSPs from the field have forced providers to stop accepting new referrals, delay the implementation of new programs and, in too many instances, shutter existing services altogether.<sup>3</sup> As a result, individuals with disabilities are left without consistent access to critical support and at a higher risk for hospitalization and institutionalization.<sup>4</sup>

This workforce crisis means that even when someone is eligible for HCBS, there may not be a person to actually provide the services. Long-term underfunding and undervaluing of the direct care workforce created gaps in availability of care, which have been exacerbated in the last several years. Workforce shortages can force individuals in the community to delay entry into the community, and can put individuals who rely on HCBS at risk of institutionalization. Several legislative approaches to the workforce crisis have been proposed, including increasing workers' wages by increasing the Federal Medical Assistance Percentage (FMAP) for HCBS with a required pass through for workers and funding increased training and career advancement opportunities for direct care workers. Other options include removing barriers to paid family caregiving by removing the restriction on this in state plan personal care services.<sup>5</sup>

Second, Medicaid's Money Follows the Person (MFP) Demonstration Program should be made permanent. The MFP program has achieved measurable success in promoting states' rebalancing of their long-term care services and in assisting people with disabilities transition from institutional placements into community settings.<sup>6</sup> The original program, created via the Deficit Reduction Act of 2005, helped over 90,000 individuals transition from institutions.<sup>7</sup> However, since 2019, Congress has funded MFP only via short-term extensions. Absent a predictable, stable base of long-term funding, many states have ceased or slowed down transitions.<sup>8</sup> Making the MFP program permanent also may enhance state's ability to plan the development of their community-based service systems more reliably, which, in turn, will promote the development of community-based services that people with disabilities need to exit facilities.<sup>9</sup>

Third, Congress should also make permanent expanded spousal impoverishment protections to prevent people with disabilities from entering institutions simply to avoid impoverishing their spouses.<sup>10</sup> Historically, the non-disabled spouses of people with disabilities who qualified for nursing facility level of care and entered Medicaid-funded nursing facilities could retain limited funds for housing, food, and other basic needs.<sup>11</sup> In 2014, spousal impoverishment protections

were temporarily extended to people with disabilities who qualify for nursing facility level of care but use HCBS rather than entering institutions.<sup>12</sup> These expanded protections are scheduled to sunset on December 31, 2023. Unless these expanded protections are made permanent, people with disabilities who need nursing facility level of care will have to enter institutions solely to avoid depriving their non-disabled spouse of the funds needed to live. Making expanded spousal impoverishment protections permanent would allow people who need nursing facility level of care to receive HCBS while living with their spouses, aging in place, and avoid costlier institutional care.

Fourth, there may be services which are now currently optional state plan services or covered via waivers that could be made mandatory Medicaid services via legislative action. A prime example of this is personal care services.<sup>13</sup> Personal care services assist people with disabilities complete critical activities of daily living. Currently, 34 states include personal care services in their state plan, but 17 states do not.<sup>14</sup> Expanding access to personal care services could materially enhance the ability of people with disabilities to avoid unnecessary institutionalization by preventing or slowing the deterioration of recipients' physical condition and lowering risks associated with people with disabilities' efforts to complete essential activities of daily living unassisted. The expansion of personal care and other HCBS (such as services for people with psychiatric disabilities who may be currently receiving services in jails or prisons or for older adults who need assistance to stay in their homes and avoid nursing homes) might have collateral economic benefits as well. The Congressional Budget Office's analysis of the economic effects of expanding home and community-based services suggests that expanding HCBS would increase the earning of most paid caregivers and many unpaid caregivers.<sup>15</sup>

While these incremental changes will improve access to HCBS and reduce the institutional bias, they will not eliminate it. The structure of Medicaid, and specifically states reliance on waivers to cap the number of individuals accessing HCBS, allows the institutional bias in Medicaid to persevere. Therefore, we also support more fundamental reforms such as replacing waivers and other optional HCBS services with a set of mandatory Medicaid services, thereby eliminating waiting lists, lowering the barriers to move state to state, and reducing the pressure to rely on unpaid, informal caregivers. In the long term, we believe that access should be based on functional need, rather than a specific diagnosis.

***B. What tools can Congress give to the Federal Government and states to help them enact policies to reduce or eliminate the institutional bias in Medicaid in the most cost-effective way? In your answer, please also address whether phasing in specific HCBS services as mandatory benefits over time or phasing in eligibility for such services by specific populations over time would be cost-effective solutions.***

As noted above, we believe there are numerous steps Congress could take to encourage states to enact policies that would reduce the institutional bias. Increasing Medicaid funding for services that fall within the definition of HCBS is a potential approach that has been used over the last several years, as is the Money Follows the Person grant program.

In the incremental expansion of Medicaid-funded HCBS, phasing in HCBS as mandatory is preferable to incremental expansion (e.g., phasing in) eligible populations. To redress Medicaid's institutional bias, the expansion of services should be driven by functional need rather than diagnosis or other population membership. Focusing on functional need is likely to maximize the impact of any service expansion to prevent unnecessary institutionalization. This also addresses gaps in services that are created when waivers are limited to groups with specific diagnoses, and thus individuals with similar or even greater functional needs are unable to access needed services.

Other incremental options include incentivizing states to propose and operate Section 1915(i) that target specific underserved populations, such as individuals transitioning out of jails or prisons, homeless individuals, and those who are at risk for psychiatric institutionalization. Section 1915(i) have a great potential to meet the needs of individuals with psychiatric disabilities, because Medicaid does not cover institutional services for many of these individuals, and 1915(i) waivers do not require a state to show that the waiver saves money compared to institutional. However, these waivers are underutilized. Congress could incentivize states to create 1915(i) waivers that provide certain well-established community-based services to individuals with mental health needs, such as Assertive Community Treatment; supported employment; peer support services; Intensive case management. housing-related activities and services. Congress could also extend the incentives that currently exist for states that establish or expand qualifying community-based mobile crisis intervention services, as defined in 1947(b) of the Social Security Act.

Any incremental expansion of HCBS should ensure that these services are inclusive of community-based behavioral health services. For example, the increased short-term FMAP for HCBS used a definition of HCBS that was inclusive community-based behavioral health services. This expansion would do much to address the needs of people with disabilities who often face unnecessary, and unnecessarily protracted institutional placements as a result of underdeveloped community-based behavioral health services.

*C. Should waitlists be eliminated for certain classes of beneficiaries immediately (such as military or veteran families with disabled children) while other waitlist reforms are implemented over a longer period of time?*

We recognize the challenge that Military families face when trying to access HCBS, as they are typically posted to a duty station for only a few years before they are moved to another. Military families, like many other families who have to move from one state to another for job-related and other reasons, may end up losing their HCBS services or their place on a waitlist, only to have to reapply in the next state.<sup>16</sup> While we caution against creating any specific preferences in Medicaid for military families, we note two approaches that could help address this problem. First, children under age 21 should be able to receive all medically necessary services via the Early and Periodic Screening, Diagnostic and Treatment benefit. There are very few services for enrollees under age 21 that can only be provided via a waiver. When children access necessary services via EPSDT, there are no waitlists or caps on enrollment. Thus,

encouraging states to create the necessary infrastructure to make services easy to access outside of a waiver will help ease access for military families with minor children.

In addition, the Tricare for Kids Coalition has been working for many years to strengthen the Department of Defense (DoD) Exceptional Family Member Program (EFMP) and its related Extended Care Health Option (ECHO) program under the military health care program, TRICARE, to ensure it truly serves the needs of military family members with disabilities.<sup>17</sup>

Ultimately, the portability problem in Medicaid is caused by the very structure of Medicaid funded HCBS and its reliance on waivers. It is an issue that affects all enrollees, and thus deserves a systemic solution. Such a solution involves reducing reliance on waivers for the delivery of HCBS and making more services mandatory. See discussion of expanding access to HCBS in Sections 1.1.A. and 1.1.B.

*D. Please provide any relevant data regarding the characteristics of waitlist populations, the costs of those individuals, and any other data relevant to waitlist reform.*

As a starting point, in FY 2020 over 650,000 individuals nationally were officially on waitlists for HCBS.<sup>18</sup> Waitlists commonly have tens of thousands of individuals on it, and some individuals wait over a decade for services. As large as these numbers are, waitlists do not capture the full breadth of the need. In states where waitlists are years long, some people may not even apply, as applying may seem futile. For example, Maryland has an Autism waiver that is limited to children under age 21, but has a typical 8 to 9 year wait. Anecdotally, we have heard of parents being told not to apply once their child is older than ten or eleven, as they will not receive services before they age out of the waiver.<sup>19</sup>

Furthermore, waitlists do not fully capture unmet need. A recent study estimates that 80% of HCBS users reported unmet need in at least one category of services normally provided via HCBS waivers, and that those with unmet needs were more likely to say they were in poor health, were more likely to visit emergency rooms, and more likely to stay overnight at a hospital or rehabilitation center.<sup>20</sup> Additionally, many mental health services do not have “official” wait lists, because the services are offered via Medicaid state plan services, and thus states are not permitted to cap or limit the number of participants. However, this does not mean that individuals are able to access services promptly. Due to limited capacity and severe workforce shortages, many Medicaid enrollees seeking mental health services have to wait months to access such services. Children wait an average of one month before being seen by a psychiatrist, and the wait for specialty services such as intensive home based services may be even longer.<sup>21</sup> As another example, in 2018, among Medicaid and CHIP enrollees, only 54% of youth with a major depressive episode with “severe role impairment” received any kind of mental health treatment within the year.<sup>22</sup>

In order to maximize the effectiveness of waitlist reforms, CMS should require that states collect more consistent, and more expansive, data regarding the operation of waiting lists and waitlisted individuals. The collection of more consistent data will promote CMS’s and others’ ability to support the development of innovative approaches to waitlist reform, scaling those

innovations as appropriate, and exploring potential interim interventions that will prevent individuals waiting for Medicaid-funded HCBS from unnecessarily entering institutions. In order to achieve these benefits associated with the collection of expanded data, CMS should require more consistency in how states report waitlist data. We also encourage CMS to include data not only about official waitlists, but also about unmet need.

**1.2 Medicaid is an essential program for those in need, and it should remain available only to those that need it. In order to ensuring that Medicaid can remain available to just those that need it:**

*A. What should Congress consider as we examine the current, allowable home equity amounts permitted by the DRA to qualify for Medicaid? Should Congress consider capping home equity values at \$500,000 (in 2005 dollars)? Should Congress consider resetting the \$500,000 to \$750,000 limit to 2022 dollars or some other level? Please provide any information on the impact of these changes or alternatives that will ensure Medicaid for those who need it.*

As long-term services and supports (LTSS) transitions towards Home and Community Based Services (HCBS), we believe the home should remain a non-countable resource at a minimum to the exemption provided in the Deficit Reduction Act of 2005 (DRA). The DRA was more restrictive than previous law, which exempted homes entirely. Under the DRA, states were given the flexibility to exempt homes of greater value given the difference in valuations throughout the country. For example, the median home price is \$633,000 in Long Island, New York, a state that has the expanded home equity limit. A lower limit will force more home sales at the time of Medicaid application, leading to increased institutionalization.

*B. What steps should Congress consider to prevent wealthy individuals from shielding assets in order to qualify for Medicaid (including but not limited to the means highlighted in the 2014 GAO report, like exploiting annuities and promissory notes to shield gifts to family members)?*

The DRA developed new standards for Medicaid eligibility, including the protection of some resources through the use of Medicaid compliant annuities and promissory notes. Our LTSS system needs substantial financial reform that provides coverage in a meaningful way without bankrupting the middle class. Until Congress undertakes substantial LTSS financing reform, we urge you to take a do-no-harm approach. One equitable measure is to eliminate the asset test, which the state of California has recently done. Eliminating the asset test would provide more straight-forward access to Medicaid LTSS and eliminate the need for promissory notes and Medicaid compliant annuities.

Importantly, qualifying for Medicaid does not mean someone does not pay for services. For example, individuals that qualify under the “medically needy” pathway for nursing homes must typically spend all of their income minus a small personal needs allowance towards the cost of care. For Section 1915(C) and other HCBS waivers with income limits, Congress should examine allowing individuals over the 300% income limit to qualify with a cost-share.

It is also important to keep in mind that Medicaid is virtually the only health care coverage that includes HCBS. Many people with disabilities rely on Medicaid services to be able to work and would not be able to work without Medicaid services. This is why there has been bipartisan support for programs such as the Medicaid Buy-in for Workers with Disabilities. This program is in dire need of reform. The Medicaid Buy-in should be offered in every state.

*C. What considerations should Congress consider when examining asset limits tied to SSI, like its lack of an inflation growth rate and marriage penalty?*

SSI provides an extremely modest cash benefit, a maximum of \$841 a month in 2022, for low-income individuals with disabilities and older adults that meet the program's strict means-tested criteria. As of July 2022, nearly 7.6 million people relied on SSI to meet their basic needs: 4.3 million working-age individuals with disabilities; 1 million children with disabilities; and 2.3 million older adults. In most states, individuals that qualify for SSI are categorically eligible for Medicaid.

Unfortunately, SSI's low, outdated resource limit of \$2,000 for individuals/\$3,000 for couples does not allow people to save for emergencies, such as a leaky roof, car repair, or other unexpected expenses. This makes it difficult for them to weather these crises. To make matters worse, the \$2,000 asset limit does not adjust for inflation every year; in fact, the limit has remained the same since 1989 even though today's cost of living is nearly 2.5 times higher. Recently, Sens. Sherrod Brown and Rob Portman introduced *The SSI Savings Penalty Elimination Act*, which would raise the asset limit to \$10,000 per individual/\$20,000 per couple. The legislation also adjusts that number for inflation every year, a critical element in today's inflationary environment. This will allow SSI beneficiaries to use their own savings to address needed emergencies when they arise. We urge you to support measures to raise, if not fully eliminate, SSI's asset test.

Additionally, several marriage penalties exist within SSI for people with disabilities.<sup>23</sup> They should be eliminated, including:

- 25% lowered asset limit for couples;
- 25% reduced benefit for couples, even though 40% of SSI beneficiaries live below poverty;
- Spousal deeming of assets and income when the spouse is not a SSI beneficiary, under which even very modest earnings of a non-SSI spouse can cause the SSI beneficiary to lose their stipend and Medicaid;
- The "holding out" rule, which can treat non-married couples as married for the purposes of SSI.

Moreover, the Disabled Adult Child (DAC) benefit also contains marriage penalties. If a DAC beneficiary marries, they lose their status, and thus their Medicare as well. As well, DAC beneficiaries have a dedicated pathway to Medicaid (see <https://www.hhs.gov/guidance/document/2002groups-deemed-be-receiving-ssi-medicaid-purposes>) which is the federal program that covers disability-specific services, supports, and

durable medical equipment that is not covered by other programs and insurers. SSI and DAC recipients often cannot marry because they need Medicaid coverage to live in the community. The only exceptions to the DAC marriage penalty are if the DAC beneficiary marries another DAC, a person on Social Security Disability Insurance, a person entitled to “old age” SSA benefits (earliest age 62), or a person receiving another “secondary” benefit. For example, a DAC beneficiary marrying someone on SSI will cause them to lose benefits. H.R.6405, *the Marriage Equality for Disabled Adults Act*, introduced by Rep. Panetta would solve this issue, and we would urge Congress to act on this legislation.

*D. MACPAC recommends making estate recovery optional. The Committee is interested in feedback on this and other options to mitigate the burden of estate recovery for states and the families of beneficiaries. Please provide comments and data on the impact of this and similar proposals.*

We strongly support eliminating estate recovery and appreciates the Committee’s focus on it in this RFI. Federal law requires state Medicaid programs to seek repayment of specific Medicaid benefits, including nursing home services and HCBS provided to beneficiaries ages 55 and older. Due to limited asset requirements associated with Medicaid, a beneficiary’s family home is often their only remaining property. Upon the beneficiary’s death, states must pursue *estate recovery* against the heirs of now deceased persons for the cost of their long-term care services. Estate recovery forces surviving family members to sell a family home where they would have otherwise resided or incur personal debt to pay off the Medicaid claims. Estate recovery also contributes to increased rates of homelessness for surviving family members.<sup>24</sup>

Because Medicaid-funded LTSS is the only realistic source of LTSS for most people, estate recovery programs do not encourage people to “plan ahead” and avoid using Medicaid—they simply punish the families of those who have or develop a health condition that requires LTSS. Estate recovery disproportionately harms economically oppressed families and communities of color, preventing these families from obtaining financial stability through home ownership. The burden also falls inequitably on families due to medical unpredictability. This unpredictability is exacerbated by inequities in our health care system that harm lower-income and older adults of color. Notably, no other public benefit program requires that correctly paid benefits be recouped from a deceased family member’s estate.<sup>25</sup>

The primary rationale of estate recovery is to recoup funds supporting state Medicaid programs. Despite this financial rationale, a 2021 MACPAC evaluation of estate recovery demonstrated that the policy is ineffective, recovering only 0.55 percent of total fee-for-service long-term care spending.<sup>26</sup>

Medicaid estate recovery should be eliminated so that low-income families are better able to retain wealth and pass it on to future generations. CCD has supported H.R. 6698, Stop Unfair Medicaid Recoveries Act, would eliminate all Medicaid estate recovery claims, except in cases where benefits were incorrectly paid.<sup>27</sup> Eliminating estate recovery will eradicate the inequitable effect of this policy on low-income families and communities of color, affording them increased financial and housing stability.



At a minimum, as MACPAC suggests, federal law should be amended to make estate recovery claims voluntary for states.<sup>28</sup> For example, although West Virginia previously attempted to eliminate and reduce the negative impacts of estate recovery, the state was unsuccessful due to current federal law.<sup>29</sup> If a state believes that estate claims are counterproductive, the state should not be forced to assess them.<sup>30</sup>

*E. Are there means to shield certain assets, like ABLE Accounts and Qualified Income Trusts, that Congress should consider expanding or making more flexible so that more beneficiaries can utilize them?*

We thank the Republican leader tremendously for her leadership and advocacy in creating, and now expanding, ABLE Accounts. Given the restrictive nature of Medicaid and SSI, particularly for working people with disabilities, Congress should continue to examine ways to protect assets of people with disabilities to ensure their dignity and independence. This includes expanding ABLE Accounts. First, we must raise ABLE account eligibility to a minimum of an onset before age 46, as included in the ABLE Age Adjustment Act. After raising the age, we recommend looking at means to further encourage savings for people with disabilities from low-income families, such as a matched savings program with federal funds.

### **1.3 In regard to ensuring that Medicaid beneficiaries can better utilize the existing eligibility pathways, so that people with disabilities are not held back by bureaucracy and red tape:**

*A. Should Congress reevaluate the asset eligibility requirements for SSI that allow for Medicaid eligibility? If Congress takes this approach, are there certain SSI-eligible populations, like those with I/DD, that should be exempted from SSI's eligibility thresholds?*

SSI remains a vital benefit to maintain access to the community. However, its restrictive methodology, which needs to be expanded, does not cover every person with a disability that requires access to HCBS. For example, a number of people with disabilities that work, but may not need SSI are limited by the current system. While “Medicaid Buy-Ins,” exist they are underutilized and often inadequate. Mandating and funding pathways for working people with disabilities is critical. Moreover, buy-ins should be income only cost share pathways without regard to asset tests. Asset tests for working people with disabilities cause a mass disincentive from reaching one's full potential and independence. At the same time, we don't believe one's “type” of disability makes one more worthy than others. Spousal income should also not be included in assigning eligibility for Medicaid Buy-In programs. The age limit of 64 to be eligible for benefits should also be eliminated.

One possible reform for people that developed a disability before the age of 22 is to allow Disabled Adult Child (DAC) beneficiaries that meet the SSI financial criterion excluding the income from the benefit to qualify. Presently, DAC beneficiaries that qualified for SSI first can retain their Medicaid, but DAC beneficiaries that were not first eligible for SSI cannot.

*B. Should Congress keep the SSI eligibility pathway for Medicaid beneficial to people with disabilities or are other, existing pathways better suited to supporting the needs of people with disabilities? Please provide further information on the value of SSI benefits for people with disabilities relative to those gained by using alternative eligibility pathways that may otherwise allow for people with disabilities to have higher levels of income and assets.*

Categorical eligibility via SSI remains critical and all states should be mandated to provide SSI beneficiaries with coverage. Presently, states have the option to provide more restrictive income methodology under Section 1902(f) of the Social Security Act otherwise known as 209(b) states. These states can provide more restrictive income limit than SSI so long as they are not more restrictive than what was contained in the state's Medicaid plan as of January 1, 1972. At a minimum, SSI should be categorically eligible in all states with 209(b) eliminated.

*C. How can Congress revitalize and incentivize the Ticket to Work eligibility pathway? Should Congress update the law to allow those over 65 to participate? How can Congress streamline eligibility pathways and raise awareness and use of this option so that more beneficiaries who want to work can better utilize it?*

*D. How can Congress use existing eligibility pathways to support people with disabilities? How can Congress streamline pathways to reduce confusion among beneficiaries and their family members and case workers? Instead of expanding eligibility to new beneficiary groups or increasing resource levels, how can Congress simplify eligibility pathways for states and beneficiaries so that they can more easily take advantage of the existing opportunities that may be available for them?*

**1.4 In order to increase uptake of LTCI among seniors and those who may benefit from such coverage and to reduce the costs of long-term care for those that do not qualify for Medicaid:**

*A. Current law limits the ability to use tax-exempt accounts, like HSAs, for covering long-term care, only allowing for them to pay medical needs associated with long-term care. Should Congress expand the opportunity for HSAs and other tax-exempt accounts to be used in long-term care?*

*B. If Congress considered expanding the use of tax-exempt accounts for long-term care coverage, should Congress consider limitations to the scope of potential services that such tax-exempt accounts can cover? Should Congress consider differentiating between the ability to use such accounts for one-time payments, like those for home modifications, as opposed to recurring payments, like those for the actual delivery of services?*

*C. Should Congress repeal federal inflation protection requirements for LTCI plans, therefore allowing for states to set inflation protection rules?*

*D. Should Congress permit holders of retirement accounts like 401(k)s or IRAs to withdraw savings early to pay for LTCI premiums and other LTSS needs without early withdrawal tax penalties?*

*E. If Congress considers permitting holders of retirement accounts, like 401(k)s or IRAs, to withdraw savings early to pay for long-term care, should Congress consider limitations on the scope of potential services for which such withdrawals may be used? For example, should Congress consider whether to differentiate between the ability to use such withdrawals for one-time payments, like those for home modifications, as opposed to recurring payments, like those for the actual delivery of services?*

*F. Should Congress allow short-term plans and other combination policies under LTCI plans under the Partnership Program?*

*G. Should Congress require the Department of the Treasury to update existing regulations for LTCI to be better aligned with models like the NAIC's LTCI models that may otherwise be out of sync with state regulations?*

**1.5 In order to build upon the existing infrastructure available to support family caregivers, including ensuring access to respite care and essential caregiving training:**

Millions of family caregivers currently provide a substantial amount of unpaid care for the people with disabilities and older adults who rely on Medicaid services or who are on waiting lists for services. As a recent report from the Community Living Policy Center at Brandeis University put it:

“The majority of individuals who need long-term services and supports (LTSS) in the US rely on unpaid assistance from family and friends. Among the approximately 11 million individuals with LTSS needs living in the community, 92% receive unpaid assistance and only 13% receive any form of paid assistance. Nationally, there are over 53 million family caregivers. The economic value of the unpaid care they provide is estimated to be over \$470 billion annually.”<sup>31</sup>

Ensuring that these family caregivers have access to the support they need to continue caregiving is crucial, even more so given the worsening HCBS workforce crisis discussed above. Respite and training, and flexibilities to allow family caregivers to become paid caregivers are all crucial pieces of ensuring this workforce has the support they need.

We also believe that it is long past time for the United States to enact a comprehensive national paid leave program that ensures that family caregivers do not have to choose between their job and being there for their loved ones. This is not simply a problem for families, it is also a problem for the economy. Family caregivers find balancing their jobs and their caregiving responsibilities very hard—research shows that many stop saving, take on more debt, and are unable to pay bills because of their caregiving responsibilities.<sup>32</sup> Others must take time off, reduce the number of hours they work, turn down promotions, or even leave the workforce

entirely.<sup>33</sup> As the country faces a labor shortage across sectors, ensuring that people have access to paid leave to provide care so that they can continue to work and employers do not need to onboard new staff has never been so important. Surveys of state programs report that paid leave has a positive or neutral effect on employers, including small businesses, and that the state programs have boosted morale and reduced turnover.<sup>34</sup> There also may be some savings to the health care system as a whole from paid leave—evidence from the paid leave program implemented in California suggests that nursing home utilization declines when paid leave programs are implemented.<sup>35</sup>

One small step towards providing additional protections for family caregivers is ensuring that all family caregivers have access to existing unpaid leave protections. While the Family and Medical Leave Act (FMLA) provides some protections for 59% of the United States workforce, there are huge gaps in that law.<sup>36</sup> Because the definition of “family” is so narrow, siblings and grandparents or grandchildren who need to take time off to help care for a child or adult with a disability cannot. Similarly, the rules for taking leave for adult children are extremely complex and often exclude situations where parents of adult children with disabilities might need to take leave.<sup>37</sup> Congress should look at this definition and ensure that it captures all family caregivers.

*A. Should Congress make respite care available to more populations within Medicaid? If so, which populations?*

Respite is not included in the definition of “medical assistance” in Medicaid.<sup>38</sup> Thus, respite is only available in Medicaid via waivers or at times via managed care organizations “in lieu of” services.<sup>39</sup> Thus, access to respite in Medicaid varies greatly by state and waiver. However, in the 1915(c) waivers, spending on respite is a tiny percentage of total waiver spending.<sup>40</sup> Caps in different states vary from children to adults and from 7 days to 180 days.<sup>41</sup> If an individual is eligible for HCBS services, regardless of specific disability (physical, intellectual, developmental, mental health), respite should be an available service for any caregivers of the individual—something that is not currently the case in many waivers and some states do not have any respite available. Given this variation, it is hard for us to recommend specific populations since state needs will vary. We would suggest that Congress instruct CMS to issue respite specific guidance and provide technical assistance to states based on the work that ACL is currently doing via the Lifespan Respite Act to develop best practices. Respite is among the most frequently requested services by families supporting individuals with I/DD. The provision of respite services will help to prevent unnecessary institutionalization and improve health equity. We recommend that respite care be made available in all states for anyone who needs it.

One potential approach to expand access to respite would be to amend the definition of “medical assistance” in 42 U.S.C. 1396d to include respite. Respite could be defined in a manner that indicates it is a service intended to directly benefit the enrollee and provide services for their medical condition. If respite were defined as “medical assistance,” then the EPSDT benefit would cover respite when medically necessary for all enrollees under 21, and states could opt to cover such services for those over 21, eliminating the need to use waivers

simply to access this benefit. States could still apply reasonable utilization management methods to this service to ensure that it is only used when it is medically necessary.

In addition, Congress could instruct CMS to expand the requirement for caregiver assessments in Medicaid 1915(i) Home and Community-Based Services (HCBS) State Plan Option programs to all Medicaid HCBS authorities, issue guidance on family caregiver assessments, and provide training and technical assistance to assist states with implementation. A caregiver assessment asks questions of the family caregiver. It is a systematic process of gathering information about a caregiving situation to identify the specific needs, strengths, and resources of the family caregiver, as well as the caregiver's ability to contribute to meeting the needs of the care recipient. Caregiver assessments can be used to identify needed services and supports, such as respite, training, and other supports.<sup>42</sup> Some states and health plans have implemented caregiver assessments. Regulations for 1915(i) require caregiver assessments.<sup>43</sup> However, CMS has not issued any guidance on caregiver assessments or conducted oversight to ensure this is happening. Moreover, to streamline HCBS and improve consistency, requirements for caregiver assessments and guidance should apply not only to 1915(i) but across all HCBS authorities.

***B. What discretionary programs for respite care are working? Which ones should be reviewed and reconsidered by Congress?***

We strongly support the respite provisions in the Older Americans Act and the Lifespan Respite Act and would urge significant additional funding for these programs. Since 2009, Congress has appropriated approximately \$2 to \$4 million annually for this program. As of 2018, initial grants of up to \$200,000 each have been awarded to eligible agencies in thirty-seven states and the District of Columbia. The original law authorized appropriations to gradually increase to \$94,810,000 by the fiscal year 2011 (H.R. 3248/P.L. 109-716). Current appropriations fall severely short of what is necessary to address the needs in our country.

We would also recommend additional investment in research on respite for different populations, specifically via the National Institute on Disability Independent Living and Rehabilitation Research (NIDILRR) at the Administration on Community Living. This could focus on less well-known caregivers, including child or teen caregivers and caregivers from different racial, ethnic, and cultural backgrounds. National experts on respite have developed a research agenda on respite, which could form the basis for new investments in respite research.<sup>44</sup>

It is also important to fund outreach efforts to family caregivers who are unaware of their options to ensure that when respite services are available, caregivers are aware of them. The RAISE Family Caregivers Act Initial Report to Congress highlights this in Recommendation 1.3.<sup>45</sup>

***C. What discretionary programs for caregiver training are working? Which programs should be reviewed and reconsidered by Congress?***

The RAISE Family Caregivers Act Initial Report to Congress pointed out that most caregiving programs are “modest in size and funding” and very population specific.<sup>46</sup> They specifically highlight ACL's NFCSP and Lifespan Respite Care Act Program, the Veterans Health

Administration's Caregiver Support Program, and HHS' Administration for Children and Families' (ACF's) Kinship Navigator Program as programs that focus specifically on the needs of caregivers. This "fragmentary and disparate approach creates missed opportunities for more comprehensive support that comes at significant risk to the ability of family caregivers to support their family members over time." We agree with this assessment and believe that a more comprehensive approach would be better.

The RAISE Family Caregiving Advisory Council, authorized by Congress, is an important mechanism that brings together agencies across the federal government, non-federal members, and input from other stakeholders to develop and implement a National Family Caregiving Strategy. The Council released its initial report to Congress on September 22, 2021, which included an inventory of federal programs that support family caregivers and 26 recommendations. The Council is in the process of finalizing the first National Family Caregiving Strategy. Congress should continue to authorize the RAISE Family Caregiving Council and provide annual appropriations to update the strategy and provide reports to Congress on implementation.

## **2.1 In order to ensure greater access to more affordable assistive technologies:**

*A. Should Congress consider authorizing Medicaid to reimburse for the cost of technologies that may have secondary uses that are not necessary or assistive, even if the primary usage is for assistive technology purposes? If so, what, if any, limitations should Congress consider when authorizing such flexibilities? Please provide any data on the cost effectiveness of such technologies.*

*B. How should Congress consider the future for assistive technologies, and how should Congress address future technologies that may not necessarily be accommodated or adopted by payers?*

We encourage Congress to consider ensuring that Medicaid is authorized to provide reimbursement for the most cost-effective technology or device that will fully meet the assistive need for which it is being procured. Current federal reimbursement policy has not kept pace with the changes in technology or the way it integrates into our daily lives. At some point, the restriction against reimbursement for devices that have uses beyond meeting documented support needs may have been a cost-saver. The proliferation of affordable multi-use devices with a wide range of functionality means that now this restriction requires Medicaid to fund the purchase of specialized devices that may cost thousands of dollars more than readily available, more cost-effective devices that have secondary uses. Congress should eliminate this restriction in favor of flexibility that will ensure more effective stewardship of Medicaid funds. This increased authority should be accompanied by guardrails to ensure that individuals receive assistive technology that will best meet their needs, rather than simply the least expensive option.

While we are supportive of states exploring these less-expensive, more readily available options and believe that doing so will allow more people to access AAC, we also caution that some AAC

devices, like speech generating devices, are not interchangeable, and each person must receive the device that meets their medical needs. Non-dedicated devices will not be equally effective for all enrollees. Important differences may exist, such as the user interface mechanism, the sound production and volume, and the durability, and the settings in which it will be used. Determinations about the appropriate device must still be individualized, based on the enrollee's needs.

We have four recommendations:

- 1) Reauthorize the Assistive Technology Act consistent with S. 2401, The 21st Century Assistive Technology Act of 2021. Jurisdiction is with the House Education and Labor Committee.
- 2) Add definition of 'assistive technology' (AT) and the requirement to assure access [to AT] to any/all authorizing or funding bills, consistent with 29 U.S.C. 3001 et seq. which says:
  - Assistive Technology (AT) is any item, device, or piece of equipment used to maintain or improve the functionality of people with disabilities, allowing them to be more independent in education, employment, recreation, and daily living activities. AT includes the services necessary to get and use the devices, including assessment, customization, repair, and training.
    - Note: A similar definition applicable to AT in K-12 educational settings is at: 20 U.S.C. 1401(1)). Also, access to "reasonable accommodations" including "services, aids, benefits and Auxiliary Aids" is protected through Section 504 of the Rehabilitation Act of 1973 and the Americans with Disabilities Act (ADA).

Rationale: Congress must make explicit that access to AT [for qualifying individuals] is essential and define it through authorizing and/or funding laws. Doing so increases the likelihood and capacity of all employers to increase access to AT and/or reduce barriers to employment, training, education and independent living for people with disabilities.

- 3) Focus on providing access to AT that is useable and interoperable.
  - Rationale: AT may need to be used by a disabled person to read text, type, speak, hear the TV, dial the phone, access training or educational materials, and more. Often, we think of AT as a computer or other electronic device and while this may be true in some instances, most AT must be used with at least one other device. This means it must be usable and interoperable so that the individual can perform the task(s) the AT is meant to support.
- 4) Assure that any/all [public] information is available in accessible formats (online and in digital formats, including via websites, mobile applications, online systems, and all forms of information and communication technology (ICT)).
  - Rationale: When Congress requires transparency, or the sharing of any information with the public, they must also assure such information is shared in accessible formats -online and in digital formats- for people with disabilities. Designing and maintaining accessible websites and other forms of ICT allows people with disabilities to receive and engage with all content that is increasingly

hosted online, including health care information, school systems, transportation options, job applications, social media, public benefit applications (e.g., health and other benefits), and information touching nearly every aspect of daily life. (See: Technology and Telecommunications Task Force – The Importance of Web Accessibility and Inclusive Design, CCD Technology and Telecommunications Task Force).

*C. Should Congress consider increasing the allowable age for qualifying for ABLE Accounts?*

Yes. As discussed above at 1.2.E, we are very grateful for the Republican leader's efforts to fix this long-standing problem. CCD strongly supports the ABLE Age Adjustment Act (H.R.121 /S.331) and urges its passage.<sup>47</sup>

**2.2 Health care accommodations must be accessible to all Americans, regardless of whether they have disabilities or not. In order to ensure federal protections that support accommodations to health care:**

*A. Should Congress strengthen oversight requirements at HHS and DOJ to ensure compliance with the law? Should Congress increase penalties for failure to meet accommodation requirements? What limits, if any, should be placed on such oversight authorities and penalties?*

We support Congress strengthening these oversight requirements and believe that one of the most effective ways to do so would be to increase staffing and capacity at DOJ and HHS's Office of Civil Rights. The disability rights section at HHS OCR does not have the capacity to review and take action on the numerous complaints they receive, and that additional capacity would be crucial.

There are also other systemic changes that Congress could consider. The current, primarily complaint-driven, system can be ineffective for people with disabilities. Exercising rights in healthcare services is dependent on proactively filing a complaint. However, people with disabilities can be reluctant to file complaints against health care entities and practitioners because they depend on those medical organizations and professionals for lifesaving or life-maintaining care. They also do not want to create an inherently adversarial relationship with providers for fear of undermining previously positive relationships or losing access to care. Considering these limitations, HHS and DOJ should be provided with the capacity to substantially increase the number of compliance reviews they undertake and enhance and target technical assistance. These actions should be directed not only to health care entities, but also to states, counties, and Medicaid managed care plans.

We do not think that limits that would reduce incentives for advocates to assist people with disabilities from protecting their rights should be placed on oversight authorities and penalties. On the contrary, because people with disabilities have minimal access to attorney or



professional advocacy assistance for individual claims of health care discrimination. It is important to encourage attorneys and others to take these cases.

It is also important that HHS update relevant regulations, such as the regulations implementing Section 504 of the Rehabilitation Act, that have not been updated in decades. We note that a bipartisan, bicameral set of Members of Congress urged HHS to update these regulations last year.<sup>48</sup> Discriminatory practices, such as discrimination in the allocation of organ transplants and the use of the Quality-Adjusted Life Year (QALY) or similar metrics like the Disability Adjusted Life Year (DALY), could be addressed in these regulations. We are also very supportive of the Protecting Health Care for All Patients Act which would ban the use of the discriminatory QALY and other similar measures.

HHS OCR should also issue a regulation requiring covered health care providers to acquire accessible equipment that complies with the Medical Diagnostic Equipment (MDE) Standards as well as develop a technical assistance document on accessible MDE. DOJ should revise its Title II and III ADA regulations requiring covered health care providers to acquire equipment that complies with the MDE Standards as well as develop a technical assistance document on accessible MDE and update the 2010 “Access to Medical Care for Individuals with Mobility Disabilities” to include information on the Access Board’s MDE Standards.

***B. Should Congress provide funding to make physical or sensory accommodations? If so, how much is needed to do so? How much should be supported by private dollars? What data exists about the costs necessary?***

While accommodations in the health care space are different than job accommodations, we believe that most accommodations would be low or no cost as research has shown they are for job accommodations.<sup>49</sup> For instance, during the pandemic, one of the most common accommodations was allowing for a support staffer to accompany a person with a disability into a health care setting. This accommodation has no cost for health care entities. Obviously, some accommodations do cost money, such as providing ASL interpreters or other language access services. Businesses should be building those costs into their overhead since they are existing requirements, but we are not opposed to tax credits or other ways to help businesses comply with the law. This might be particularly useful in the space of accessible medical equipment and ensuring that medical practices can afford the equipment detailed in the recently finalized standards from the United States Architectural and Transportation Barriers Compliance Board.<sup>50</sup>

It would also be helpful for Congress to create a technical assistance center, like the Job Accommodation Network (JAN) to help health care entities understand their obligations and help them work through questions.<sup>51</sup> Given the involvement of CMS in many of these issues, the center could also work with that agency to address system issues (such as a recently proposed billing code to help with accessing needed operating rooms for some dental care for people with disabilities). It would be necessary for the center to also be able to work with the general public and, like JAN, conduct outreach and training.

Congress should also begin again to fund the adoption and implementation of disability cultural-competent curricula in all undergraduate medical and allied health professional education as well as post-graduate residency and fellowship programs conducted in over 1100 teaching hospitals, ensuring that as many entities as possible can build out their competencies. The legislative mechanism for doing so exists, in part, in Section 5307 of the Patient Protection and Affordable Care Act, 42 U.S.C.A. § 293e. Section 5307 conferred authority through the Administrator of the Health Resources and Services Administration, to make awards of grants, contracts, or cooperative agreements to public and nonprofit private entities (including tribal entities) for the development, evaluation, and dissemination of research, demonstration projects, and model curricula for cultural competency, prevention, public health proficiency, reducing health disparities, and aptitude for working with individuals with disabilities training for use in health professions schools and continuing education programs, and for other purposes HHS may determine as appropriate. *Id.* § 293e(a)(1). We recommend that such curricula incorporate the Core Competencies on Disability for Health Care Education drafted by the Alliance for Disability in Health Care Education.<sup>52</sup> Federal funding is required to implement this recommendation. We also recommend that the healthcare accreditation bodies, themselves, take responsibility for increasing their understanding of the effects of implicit disability bias, racism, and ableism on health outcomes for multi-marginalized communities because addressing inequalities is central to improving care quality.

*C. How should Congress address support for training health care professionals on how to accommodate people with disabilities? Should medical schools and other continuing medical education opportunities be responsible for ensuring providers are educated on such issues? Are federal funds needed for such efforts?*

The lack of training about people with disabilities has led to huge access and quality of care issues-- only 40.7% of physicians report feeling “very confident” in their ability to provide the same quality of care to their patients with disabilities.<sup>53</sup> Over 75% of individuals with disabilities report experiencing barriers that impede them from using healthcare and wellness services.<sup>54</sup> This lack of knowledge, as the memo points out, results in inaccessible services and poor outcomes. We were very supportive of and glad to see the recent change around reimbursement for support staffing during a hospitalization.

A recent study found that only 52% of the 75 medical schools that responded to the research study had some form of disability awareness education for students.<sup>55</sup> This needs to change. We would recommend reauthorizing section 741 of the Public Health Service Act as a preliminary step.

Another way to help address these disparities is recruitment of people with disabilities as health care professionals. While approximately a quarter of the U.S. population has a disability, only 3.1% of physicians<sup>56</sup> and 2.7% of medical students are people with disabilities.<sup>57</sup> We would urge Congress to provided targeted funding to increase the number of physicians, nurses, and other health care professionals who have disabilities. It would also be helpful for DOJ and the Department of Education to provide additional guidance on reasonable accommodations for people with disabilities in health education settings, including medical schools. These steps

would not only help address the disparities in the number of health care professionals with disabilities—having more health professionals with disabilities would also help build awareness within the professions.

*D. How have telehealth and other remote monitoring technologies been used to improve accessibility to health care services for people with disabilities? How did the utilization of such services during the pandemic improve access to care or mitigate a worsening of access to care? What should Congress consider when examining future extensions of telehealth and remote monitoring authorizations?*

The expansion of telehealth and other remote technologies during the pandemic was both helpful for many people with disabilities and limiting or ineffective for others. The CCD Health Task Force developed principles on Telehealth that we recommend guide any legislative efforts.<sup>58</sup>

Remote monitoring has great potential to increase the independence of people with disabilities while ensuring their well-being in the community. Remote patient monitoring can be used to monitor blood glucose levels in patients with diabetes, manage other chronic conditions, enable individuals with developmental disabilities learn skills with more independence, as well as to provide limited acute services. It is also important to incentivize data collection regarding the use of remote monitoring so that its use can be appropriately targeted and adjusted to those situations when remote monitoring is beneficial to patients rather than merely a way to cope with widespread workforce shortages that can limit the availability of in-person care. As with telemedicine generally, it is important that all appropriate accessibility, privacy, and freedom of choice protections accompany the use of remote monitoring. These and other guardrails will facilitate the expansion of remote patient monitoring in a way that promotes positive health outcomes without compromising patient privacy and decision-making.

### **3.1 In order to make workplace accommodations more affordable and accessible for employers so that workplaces can be accessible to all workers:**

*A. Should all federal departments and independent agencies be required to have accommodation programs similar to DOD's Computer/Electronic Accommodations Program?*

Workers with disabilities in all federal departments and independent agencies should be eligible to apply for workplace accommodations from the Computer/Electronic Accommodations Program (CAP) at the Department of Defense. Following the National Defense Authorization Act of October 2000, Congress granted CAP the authority to provide assistive technology, devices and support services free of charge to Federal agencies that have a partnership agreement with CAP. Effective October 1, 2020, CAP is a procurement resource funded only to provide assistive technology to Department of Defense employees, and active-duty Service members.

In accordance with Executive Order (EO) 13985, <https://www.whitehouse.gov/equity/>, federal agencies were required to issue and pursue their Equity Action Plans and to conduct equity assessments, to uncover where systemic barriers to access may exist. In the EO's mission to provide equity for all Americans, Equity Action Plans were required to include accountability mechanisms and to identify success metrics and key milestones toward progress. The underfunding of the DOD CAP cannot continue and is a clear inequity that must be addressed to enable people with all disabilities to obtain greater independence for themselves and their families and to be able to engage in their communities and participate more fully in society, just like their non-disabled peers.

*B. Should Congress consider tax credits or tax deductions for employers to support workplace accommodations? If yes, what restrictions, if any, should be made on how such tax credits or deductions are used? Similarly, should such tax credits or deductions be limited to small employers or other categories of employers?*

The CCD Employment Task Force has endorsed the Disability Employment Incentives Act which involves tax credits for accessibility (Sec. 44, Sec. 190 IRS Code) and enhanced work opportunity tax credits.

Thank you for the opportunity to comment on these important issues. CCD looks forward to working with you on these issues in the future.

Sincerely,

Access Ready  
Allies for Independence  
American Association on Health and Disability  
American Council of the Blind  
American Foundation for the Blind  
Assistive Technology Industry Association (ATIA)  
Association of People Supporting Employment First (APSE)  
Association of University Centers on Disabilities  
Autism Society of America  
Autistic Self Advocacy Network  
Bazelon Center for Mental Health Law  
Caring Across Generations  
Christopher & Dana Reeve Foundation  
Cure SMA  
Disability Rights Education and Defense Fund  
Easterseals  
Epilepsy Foundation  
Family Voices  
Justice in Aging  
Lakeshore Foundation  
National Association of Councils on Developmental Disabilities

National Association of State Head Injury Administrators  
National Disability Institute  
National Down Syndrome Congress  
National Health Law Program  
National PLAN Alliance  
Paralyzed Veterans of America  
RespectAbility  
Telecommunications for the Deaf & Hard of Hearing (TDI)  
The ALS Association  
The Arc of the United States  
United Cerebral Palsy  
United Spinal Association  
United States International Council on Disabilities

---

<sup>1</sup> See, e.g., *PGA Tour, Inc. v. Martin*, 532 U.S. 661, 674-75 (2001) (recognition of historical isolation and segregation of people with disabilities prompting passage of the ADA); see also *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 601 (1999) (“[C]onfinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment.”).

<sup>2</sup> National Core Indicators Intellectual and Developmental Disabilities 2020 Staff Stability Survey, available at [https://www.nationalcoreindicators.org/upload/core-indicators/2020StaffStabilitySurveyReport\\_FINAL.pdf](https://www.nationalcoreindicators.org/upload/core-indicators/2020StaffStabilitySurveyReport_FINAL.pdf).

<sup>3</sup> American Network of Community Options & Resources, The State of America’s Direct Support Workforce 2021, available at [https://www.ancor.org/sites/default/files/the\\_state\\_of\\_americas\\_direct\\_support\\_workforce\\_crisis\\_2021.pdf](https://www.ancor.org/sites/default/files/the_state_of_americas_direct_support_workforce_crisis_2021.pdf).

<sup>4</sup> Dan Goldberg, POLITICO, ‘People Will Die Waiting’: America’s System for the Disabled is Nearing Collapse (Aug. 10, 2022) <https://www.politico.com/news/2022/08/10/americas-system-for-the-disabled-is-nearing-collapse-00050713>

<sup>5</sup> 42 U.S.C. § 1396d(24) prohibits provision of personal care services by individuals who are a member of the individual’s family. We recognize that if this prohibition is removed, there are risks, including the risk that family will be compelled to provide services when such arrangements are not designed by the enrollee and are not in the enrollees’ interests. However, we believe that such risks can be managed by enforcing prohibitions on compelling natural supports and creating and implementing person-centered plans.

<sup>6</sup> Mathematica, Money Following the Person Demonstration; Overview of State Grantee Progress, January to December 2016 (Sep. 2017), <https://www.medicaid.gov/sites/default/files/2019-12/2016-cross-state-report.pdf>.

<sup>7</sup> See, e.g., MaryBeth Musumeci, et al. , *KFF Issue Brief: Medicaid’s Money Follows the Person Program: State Progress and Uncertainty Pending Federal Funding Reauthorization*, Nov. 25, 2019, <https://www.kff.org/medicaid/issue-brief/medicaids-money-follows-the-person->

---

program-state-progress-and-uncertainty-pending-federal-funding-reauthorization/ (noting states' reports of service discontinuation if federal funding expires).

<sup>8</sup> Victoria Peebles and Johanna Dole, Mathematica, *Money Follows the Person: State Transitions as of December 31, 2020* (July 20, 2022), <https://www.medicaid.gov/medicaid/long-term-services-supports/downloads/mfp-2020-transitions-brief.pdf>.

<sup>9</sup> Id. See, e.g., MaryBeth Musumeci et al, Kaiser Fam. Found., *Medicaid's Money Follows the Person Program: State Progress and Uncertainty Pending Federal Funding Reauthorization*, Nov. 25, 2019, <https://www.kff.org/medicaid/issue-brief/medicaids-money-follows-the-person-program-state-progress-and-uncertainty-pending-federal-funding-reauthorization/> (noting states' reports of service discontinuation if federal funding expires).

<sup>10</sup> Justice in Aging, *Make the Expanded Spousal Impoverishment Protection Permanent*, <https://justiceinaging.org/wp-content/uploads/2019/01/Justice-in-Aging-Federal-Spousal-Impoverishment-Fact-Sheet-11-8-18.pdf>.

<sup>11</sup> See Kaiser Family Foundation, *Medicaid's Role in Nursing Home Care*, at <https://www.kff.org/infographic/medicaids-role-in-nursing-home-care/>.

<sup>12</sup> Pub. L. No. 111-148, § 2404.

<sup>13</sup> 42 U.S.C. § 1396(d)(24)

<sup>14</sup> Kaiser Fam. Found., *Medicaid Benefits: Personal Care Services, 2018*, <https://www.kff.org/medicaid/state-indicator/personal-care-services/?currentTimeframe=0&sortModel=%7B%22colId%22:%22Location%22,%22sort%22:%22asc%22%7D>

<sup>15</sup> See Congressional Budget Office, *Economic Effects of Expanding Home- and Community-Based Services in Medicaid*, Nov. 2021, at 5, <https://www.cbo.gov/system/files/2021-11/57632-Medicaid.pdf> (analysis performed with HCBS expansion proposed by Build Back Better Act H.R. 5376).

<sup>16</sup> <https://www.gao.gov/products/gao-22-105204>

<sup>17</sup> <https://tricareforkids.org/report-americas-military-readiness-and-the-essential-role-of-medicaid/>

<sup>18</sup> Molly O'Mally Watts et al., *State Policy Choices About Medicaid Home and Community-Based Services Amid the Pandemic* (March 2022), <https://www.kff.org/report-section/state-policy-choices-about-medicaid-home-and-community-based-services-amid-the-pandemic-issue-brief/>

<sup>19</sup> Recently, Maryland passed the "End the Wait Act," requiring the Maryland Department of Health to develop plans to reduce the waitlist or registry for certain waiver programs by 50% beginning in fiscal year 2024.

<https://mgaleg.maryland.gov/mgawebsite/Legislation/Details/SB0636?ys=2022RS>

<sup>20</sup> F.M. Gardiner, F.M. Community Living Policy Center, Brandeis University, *Care Can't Wait: How Do Inadequate Home- and Community-Based Services Affect Community Living and Health Outcomes?* (2021), <https://heller.brandeis.edu/community-living-policy/images/pdfpublications/care-cant-wait.pdf>.

<sup>21</sup> United States Senate, Committee on Finance, *Mental Health Care in the United States: the Case for Federal Action* (March 2022), <https://www.finance.senate.gov/imo/media/doc/SFC%20Mental%20Health%20Report%20March%202022.pdf>

---

<sup>22</sup> MACPAC, Chapter 3: Access to Behavioral Health Services for Children and Adolescents at 87 (June 2021), <https://www.macpac.gov/wp-content/uploads/2021/06/Chapter-3-Access-to-Behavioral-Health-Services-for-Children-and-Adolescents-Covered-by-Medicaid-and-CHIP.pdf>

<sup>23</sup> The New York Times, Tammy La Gorce, Seeking Marriage Equality for People with Disabilities (Aug 2022), <https://www.nytimes.com/2022/08/25/style/marriage-equality-disabled-people.html>.

<sup>24</sup> Justice in Aging, Medicaid Estate Claims: Perpetuating Poverty and Inequality for a Minimum Return (Apr 2021), <https://justiceinaging.org/wp-content/uploads/2021/04/Medicaid-Estate-Claims.pdf>.

<sup>25</sup> *Id.*

<sup>26</sup> MACPAC, Chapter 3: Medicaid Estate Recovery: Improving Policy and Promoting Equity (Mar 2021), <https://www.macpac.gov/wp-content/uploads/2021/03/Chapter-3-Medicaid-Estate-Recovery-Improving-Policy-and-Promoting-Equity.pdf>.

<sup>27</sup> H.R. 6698, Stop Unfair Medicaid Recoveries Act of 2022, <https://www.congress.gov/bill/117th-congress/house-bill/6698/text>.

<sup>28</sup> *Supra* note 26.

<sup>29</sup> *West Virginia v. United States HHS*, 132 F. Supp. 2d 437, 441 (S.D. W. Va. 2001); *West Virginia v. Thompson*, 475 F.3d 204, 214 (4th Cir. 2007).

<sup>30</sup> *Supra* note 24.

<sup>31</sup> Community Living Policy Center, Brandeis University, Joseph Caldwell, *Reducing Costs for Families and States by Increasing Access to Home and Community-Based Services* (Mar 2022) <https://heller.brandeis.edu/community-living-policy/images/reducing-cost-hcbs.pdf>

<sup>32</sup> AARP and National Alliance for Caregiving, *Caregiving in the US* (May 2020), <https://www.caregiving.org/wp-content/uploads/2021/01/full-report-caregiving-in-the-united-states-01-21.pdf>. For specific examples of this issue, see Washington Post, Caring for Aging Parents, Sick Spouses in Keeping Millions Out of Work (Apr 2022), <https://www.washingtonpost.com/business/2022/04/04/caregiving-economy-adults-work/>

<sup>33</sup> Caregiving in the United States, *supra* note 32.

<sup>34</sup> National Partnership for Women and Families, *Paid Leave Works: Evidence from State Programs* (Feb 2022), <https://www.nationalpartnership.org/our-work/resources/economic-justice/paid-leave/paid-leave-works-evidence-from-state-programs.pdf>; Ann P. Bartel, et. al, *The Impact of Paid Family Leave on Employers: Evidence from New York* (Apr 2021), [https://www.nber.org/papers/w28672?utm\\_campaign=ntwh&utm\\_medium=email&utm\\_](https://www.nber.org/papers/w28672?utm_campaign=ntwh&utm_medium=email&utm_)

<sup>35</sup> Journal of Policy Analysis and Management; Kanika Arora and Douglas Wolf; *Does Paid Family Leave Reduce Nursing Home Use? The California Experience*; Vol. 37, Issue 1 (Nov 2017); <https://onlinelibrary.wiley.com/doi/abs/10.1002/pam.22038>.

<sup>36</sup> RAISE Family Caregiving Advisory Council, Initial Report to Congress (Sept 2021), [https://acl.gov/sites/default/files/RAISE-InitialReportToCongress2021\\_Final.pdf](https://acl.gov/sites/default/files/RAISE-InitialReportToCongress2021_Final.pdf).

<sup>37</sup> Department of Labor, Questions and Answers concerning the use of FMLA leave to care for a son or daughter age 18 or older (cited Sept 2022), <https://www.dol.gov/agencies/whd/fmla/faq/adult-child>.

<sup>38</sup> See generally 42 U.S.C. § 1396d.

<sup>39</sup> See 42 U.S.C. § 1396d(n); MACPAC, *Financing Strategies to Address the Social Determinants of Health in Medicaid* (May 2022), <https://www.macpac.gov/wp->

---

content/uploads/2022/05/SDOH-Issue-Brief\_May-2022.pdf (noting use of in lieu of authority to fund respite services).

<sup>40</sup> National Academy for State Health Policy, Kimberly Hodges, *State Respite Care Spending Is Low in Most Home and Community-Based 1915(c) Waivers* (Jul 2022), <https://www.nashp.org/state-respite-care-spending-for-older-adults/>

<sup>41</sup> National Academy for State Health Policy, Kimberly Hodges and Zack Gould, *State Caps on Respite Waiver Services Vary Greatly* (July 2022) <https://www.nashp.org/state-caps-on-respite-waiver-services-vary-greatly/>.

<sup>42</sup> K. Kelly, N. Wolfe, M.J. Gibson, L. Feinberg, Listening to Family Caregivers: The Need to Include Family Caregiver Assessment in Medicaid Home and Community Based Service Waiver Programs (Washington, DC: AARP Public Policy Institute, Family Caregiver Alliance, December 2013), available at [http://www.aarp.org/content/dam/aarp/research/public\\_policy\\_institute/ltc/2013/the-need-to-include-family-caregiver-assessment-medicare-hcbs-waiver-programs-report-AARP-ppi-ltc.pdf](http://www.aarp.org/content/dam/aarp/research/public_policy_institute/ltc/2013/the-need-to-include-family-caregiver-assessment-medicare-hcbs-waiver-programs-report-AARP-ppi-ltc.pdf).

<sup>43</sup> Final Rule on 1915(i) State Plan Home and Community-Based Services, 5-Year Period for Waivers, Provider Payment Reassignment, Setting Requirements for Community First Choice, and 1915(c) Home and Community-Based Services Waivers - CMS 2249-F and 2296-F.

<sup>44</sup> ARCH National Respite Network and Resource Center, A Research agenda for Respite Care (Oct 2015), [https://archrespite.org/images/docs/2015\\_Reports/ARCH\\_Respite\\_Research\\_Report\\_web.pdf](https://archrespite.org/images/docs/2015_Reports/ARCH_Respite_Research_Report_web.pdf).

<sup>45</sup> RAISE Council Initial Report to Congress, *supra* note 36.

<sup>46</sup> *Id.*

<sup>47</sup> Consortium for Constituents with Disabilities, The ABLE Age Adjustment Act Fact Sheet (Feb 2022), <https://c-c-d.org/fichiers/ABLEAge-FactSheet2-1-2022.pdf>.

<sup>48</sup> Letter to Secretary Azar and Attorney General Barr on Disability Non-Discrimination in Health Care (Mar 2020), [https://chrissmith.house.gov/uploadedfiles/2020-03-25\\_bipartisan\\_bicameral\\_letter\\_to\\_hhs\\_and\\_doj\\_-\\_covid-19\\_and\\_disability\\_discrimination.pdf](https://chrissmith.house.gov/uploadedfiles/2020-03-25_bipartisan_bicameral_letter_to_hhs_and_doj_-_covid-19_and_disability_discrimination.pdf).

<sup>49</sup> Job Accommodation Network, Workplace Accommodations: Low Cost, High Impact (Oct 2020), <https://askjan.org/topics/costs.cfm>.

<sup>50</sup> U.S. Architectural and Transportation Barriers Compliance Board, Final Rule: Medical Diagnostic Equipment Standards, 36 CFR part 1195 (Jan 2017).

<sup>51</sup> The Job Accommodation Network, <https://askjan.org>

<sup>52</sup> See Core Competencies on Disability for Health Care Education Ohio State Nisonger Center ([osu.edu](https://osu.edu)).

<sup>53</sup> Iezzoni LI, Rao SR, Ressler J, Bolcic-Jankovic D, Agaronnik ND, Donelan K, et al. Physicians' Perceptions Of People With Disability And Their Health Care. *Health Affairs*. 2021 Feb 1;40(2):297–306

<sup>54</sup> Disability and Health | Healthy People 2020 [Internet]. Office of Disease Prevention and Health Promotion. [cited 2022 Jan 27]. Available from: <https://www.healthypeople.gov/2020/topicsobjectives/topic/disability-and-health/national-snapshot>

<sup>55</sup> Seidel E, Crowe S. The State of Disability Awareness in American Medical Schools. *Am J Phys Med Rehabil*. 2017 Sep;96(9):673–6.



---

<sup>56</sup> Estimated Prevalence of US Physicians With Disabilities | Health Care Workforce | JAMA Network Open | JAMA Network [Internet]. [cited 2022 Jan 27]. Available from: <https://jamanetwork.com/journals/jamanetworkopen/fullarticle/2777420>

<sup>57</sup> Prevalence of Self-disclosed Disability Among Medical Students in US Allopathic Medical Schools | Medical Education and Training | JAMA | JAMA Network [Internet]. [cited 2022 Jan 27]. Available from: <https://jamanetwork.com/journals/jama/fullarticle/2589334>

<sup>58</sup> Consortium for Constituents with Disabilities, Health Task Force Telehealth Principles (Jul 2020), <https://www.c-c-d.org/fichiers/CCD-Health-TaskForce-Telehealth-Principles-July-2020.pdf>.